

**THE EXPERIENCES OF INTIMACY FOR ADULTS WITH
ACQUIRED COMMUNICATION DISORDERS USING
AUGMENTATIVE AND ALTERNATIVE COMMUNICATION
(AAC)**

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ABSTRACT

Background: Intimacy has been described as a primary psychological need. In order to function “normally”, we require repeated, positive interactions with those with whom we are in a caring relationship. To date, research looking at adults with acquired communication disorders who use Augmentative and Alternative Communication (AAC) has focussed on device selection, providing functional communication, acceptance and use of AAC, and caregiver support. There is a lack of research into how the use of AAC impacts the personal and social lives of adults with acquired communication disorders. The aim of this study was to explore the experience of intimacy and intimate communication from the perspective of individuals who have an acquired communication disorder and use AAC, and from the perspective of their partners.

Method: A phenomenological research approach was used to address the study aim. Individual semi-structured interviews were conducted with five participants with an acquired communication disorder who had used AAC some or all of the time and with their five partners. Joint semi-structured interviews were conducted with four of the couples. Thematic analysis was used to identify themes within the data.

Results: Eight key themes emerged from the data, namely *effort, importance, time, closeness, adaptation, emotion, identity, and privacy*. Within these themes participants discussed how AAC has been both beneficial and detrimental to their intimacy and intimate communication.

Discussion and Conclusion: This study has identified a number of important areas that professionals need to consider in order to facilitate successful intimacy and intimate

communication for adults with acquired communication disorders who use AAC and for their partners. Future research is needed to identify specific ways speech-language therapists can help this population adapt their communication to make the best use of AAC for intimacy and intimate communication.

INTRODUCTION

Developing and maintaining intimate relationships is important for human health and well-being (Lippert & Prager, 2001; Miller & Perlman, 2009; Prager, 1995).

Communication is a central factor in intimate relationships. This is demonstrated by the link between perceptions of intimacy with self-disclosure and partner responsiveness (Kouneski & Olson, 2004; Lippert & Prager, 2001; Manne et al., 2004; Marston, Hecht, Manke, McDaniel, & Reeder, 1998; Miller & Perlman, 2009). Research has examined intimacy in relationships between healthy adults, and has also focussed on relationships where one partner has a neurological or physical illness (Manne et al., 2004; Wright, 1998). This research has indicated that high levels of intimacy and affection leads to better quality of life outcomes.

While communication has been identified as being central to intimacy, little research has investigated how intimacy is affected by the onset of an acquired communication disorder. For many couples, communication is irreversibly altered after the onset of a neurological disease or disorder, a stroke, or traumatic head injury. Often natural speech is significantly reduced or lost, and alternative methods of communication are required to provide adequate levels of communication (Beukelman & Mirenda, 2005).

To date, research into acquired communication disorders and augmentative and alternative communication (AAC) has focussed on what types of AAC are appropriate, how readily AAC is used and incorporated into the lives of users and families, and how these new forms of communication can be used in maintaining everyday roles at work and in

wider society. What is missing from the research is how adopting new forms of communication impacts on the connection and communication in intimate relationships. For adults with acquired communication disorders who rely on AAC, the ability to express thoughts and feelings differs from those without communication impairments. Identifying changes or strategies adopted by users of AAC and their significant others in maintaining their intimate relationships, will allow professionals to develop an understanding of the needs of this specific population and the role AAC plays in maintaining intimacy. This thesis reports the current research on intimate relationships and communication and explores the experiences of intimacy and intimate communication for adults with acquired communication disorders using AAC and for their partners.

LITERATURE REVIEW

Intimacy

Intimacy has been described as a primary psychological need (Lippert & Prager, 2001) and in order to live fulfilling lives researchers have indicated we require repeated, positive interactions with those with whom we are in a caring relationship (Miller & Perlman, 2009). Participating in and maintaining personal relationships is widely recognised as a fundamental aspect of human existence (Reis, Collins, & Berscheid, 2000). The vast majority of people desire to be liked and loved by others, and spend a considerable amount of time and energy developing and maintaining relationships with others (DeVito, 1995). Relationships do not just happen, even those with family need to be nurtured and developed, with emotional investment required from both parties if the relationship is going to be equally rewarding and fulfilling.

The quality of intimacy within personal relationships influences our overall health and well-being, reinforcing the importance of maintaining intimate personal connections. People with unfulfilled social needs have shorter life spans, and those who are involved in intimate relationships have fewer stress-related symptoms and better overall health (Miller & Perlman, 2009; Prager, 1995). Frequent and positive intimate interactions within an intimate relationship help individuals feel valued and wanted, which leads to positive feelings about the relationship even when individuals are not engaged in contact (Prager, 1995). This intimacy can also assist in the development of other aspects of

relationships such as trust, affection, and cohesiveness, all of which work together to strengthen the functioning of a relationship (Prager, 1995).

Establishing a definition of intimacy, and ascertaining the precise nature of how intimate relationships vary from other relationships, has been widely debated in the literature. Miller and Perlman (2009) suggested that being part of a couple in an intimate relationship means that the lives of the individuals are interconnected in a more profound way than in other relationships. The interdependence that exists in intimate relationships results in individual needs, wants, and behaviours having a more meaningful effect on the other person, and can affect what the other partner wants or chooses to do. This interdependence results in the couple having a different view of themselves, identifying as a couple rather than individuals in a relationship (Miller & Perlman, 2009). According to Miller and Perlman (2009), an intimate relationship can be separated from other relationships in six particular aspects that, if absent, will result in less meaningful and gratifying relationships. The six aspects are: knowledge, caring, interdependence, mutuality, trust, and commitment.

Intimate interactions can be differentiated from other forms of contact due to the presence of self-revealing behaviour, positive involvement with the other, and shared understandings (Mashek & Aron, 2004). These aspects play an important role in the makeup of intimacy. Self-revealing behaviour is described as being either verbal or non-verbal behaviour where one partner willingly opens themselves to reveal deeply personal emotions, and it is the willingness to allow the other to observe these personal feelings that

in part constitutes an intimate interaction (Mashek & Aron, 2004). Positive involvement is also a requirement, which again can be expressed through verbal or non-verbal communication, and entails the partner providing their full attention during the interaction. Couples' intimate interactions are also demonstrated through shared understanding of some aspect of each other, whether thoughts, feelings, or beliefs. This deeper knowledge of the other person will also continue to shape future interactions, through verbal or non-verbal disclosures (Mashek & Aron, 2004).

The term 'disclosure' is central to several definitions of intimacy (Lippert & Prager, 2001; Manne et al., 2004). Manne et al. (2004) identified self-disclosure and partner responsiveness as being key elements in perceptions of intimacy. Kouneski and Olson (2004) suggest communication as being vital in the development and evolution of intimacy. These researchers state that how a couple communicates is a crucial factor in intimacy, and communication needs to be assertive and respectful to promote intimacy. Marston et al. (1998) investigated the subjective experiences of intimacy. The findings suggested that intimacy is made up of three components, self-disclosure, communicating affection, and behavioural interdependence. Moss and Schwebel (1993) found that communication and self-disclosure as reoccurring themes or facilitators in at least 50% of 61 published definitions of intimacy. From this review, Moss and Schwebel (1993) proposed the following definition, "Intimacy in enduring relationships is determined by the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship" (p.33).

Effective communication is important in the development and maintenance of interpersonal relationships and specific forms of communication are central to defining a relationship as intimate. Intimate relationship cannot be established and maintained without the disclosure of personal information (Miller & Perlman, 2009). This personal information may include discussing life history in the early stages of the relationship, and may develop to feelings, secrets, or desires as the relationship develops. Disclosure of personal information forms the knowledge of each other that is a key component of the intimate relationship, which may not be possible without a sense of caring for each other that goes beyond the level of caring in a non-intimate relationship (Miller & Perlman, 2009).

Intimacy and Disability

Disability is defined as “...an umbrella term, covering impairments, activity limitations, and participation restrictions... a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives” (WHO, 2010). Disability can come in many forms and can be either congenital or acquired through injury or disease. Many studies have been conducted focussing on a variety of disabilities and examining the impact they have on relationships and the role disability plays in intimacy for the couples involved.

Intimacy and Dementia

Dementia is an acquired syndrome of chronic and progressive symptoms resulting from brain disease, and is defined as “an impairment in short- and long-term memory with related changes in abstract thinking, judgement, other higher cortical functions, or

personality that causes significant social and occupational impairments” (Bourgeois, 2005, p. 199). There are many different causes of dementia, from neurodegenerative diseases, to vascular diseases and neurologic disorders, all presenting with a gradual onset of symptoms (Bourgeois, 2005). Alzheimer’s disease is the most common form of dementia with memory loss being the main indicator, resulting in a disturbance in behaviour, language and communication abilities, especially as the disease progresses (Bourgeois, 2005).

Affection and sexual intimacy is different in couples when a spouse has Alzheimer’s disease in comparison to relatively healthy couples (Wright, 1998). Wright (1998) conducted a longitudinal study that followed a group of 30 couples over a period of two years commencing five years after the onset of Alzheimer’s. They compared the couples’ ratings of affection and marital intimacy with a group of 17 relatively healthy aged-matched couples. Participants completed a retrospective review of the time prior to the onset of Alzheimer’s disease, and a review of present day levels of affection. The study found that, among couples who experience higher levels of affection and intimacy, the spouse with Alzheimer’s disease was able to remain at home for longer. This finding suggests the importance of emotional connection, meaning caregivers were able to maintain the emotional strength required to care for their spouse, while coping with decreased emotional support from their partner. Although Wright (1998) clearly showed that disorders affecting the cognitive health of a spouse change intimacy in comparison to healthy couples, the results from this study indicate that maintaining a high level of affection and intimacy leads to better quality of life outcomes.

Strong intimate bonds can result in less stressful experiences for caregivers of partners with dementia (Baikie, 2002). In a review of the literature on care giving in dementia, Baikie (2002) found that previous research literature in this area focussed mainly on the negative outcomes of care giving, and that the qualities of marital relationships themselves were mostly overlooked. The review identified the areas of social support, anticipatory grief, and social death, to be particularly important aspects when determining the impact dementia has on marital relationships. It was highlighted that carers who were in relationships that had lesser levels of intimacy before the onset of dementia experienced higher levels of depression and perceived strain, indicating that relationships without strong intimate bonds may result in a more stressful experience for the caregiver (Baikie, 2002). Baikie concluded that relationships, in which one partner is caring for the other with dementia, need to be viewed as intimate relationships potentially entailing considerable emotional and interpersonal strain rather than just behavioural disturbances. Changing the perspective on these relationships, and providing emotional support as well as practical support, may be required to help carers deal with the loss of intimacy and work towards maintaining their relationship (Baikie, 2002).

Intimacy and Hearing Loss

Multiple studies have reported a significant impact of acquired hearing loss on families (Anderson & Noble, 2005; Hallam, Ashton, Sherbourne, & Gailey, 2008; Hetu, Jones, & Getty, 1993; Yorgason, Piercy, & Piercy, 2007). Findings suggest that deafness often impacts the communication in close relationships (Hetu et al., 1993). The negative impact of

hearing loss included tension and adaptation difficulties which in-turn impacted on the quality of interpersonal communication among couples (Hetu et al., 1993).

Hearing loss has a detrimental effect on the quality of marriages (Hallam, Ashton, Sherbourne, & Gailey (2008). Fifty percent of participants in their qualitative study indicated hearing loss had negatively affected their marriage, and a similar percentage showed evidence of interpersonal stress (Hallam et al., 2008). Similarly, Anderson and Noble (2005) reported that intimate relationships suffered when negative behaviours were attributed to hearing impaired spouses. Both of these studies concluded that there is a need for more research into the impact of hearing impairment on intimate relationships and that those couples who are able to accept and/or adapt to a communication disorder have higher levels of relationship satisfaction.

Resilience and communication were identified as key aspects in the maintenance of strong relationships in the study conducted by Yorgason et al. (2007). Yorgasen et al. explored the relationships of couples where one person had a hearing impairment to examine communication and processes of resilience as they dealt with their experiences. They discussed how communication difficulties due to hearing impairment acquired after the establishment of the relationship may be particularly challenging for couples to overcome. The results from the study indicated that those couples who were able to come to terms with the acquired communication difficulties were of the belief that their relationships were strengthened by the experience. It was also indicated that developing an understanding how couples with strong relationships, that are rich in communication,

function when their relationships are operating at their optimum is of importance. With this understanding, professionals will be better able to appreciate and help those couples who may be struggling due to loss or life changes that impact on how they work as a couple (Yorgason et al., 2007).

Intimacy and Other Life Changing Events

Intimacy and Trauma

Emotional trauma has a significant effect on intimate relationships (Goff et al., 2006). The impact of emotional trauma is likely to depend on the person involved, the type of traumatic event, and the support system that is available during and afterwards. Goff et al. (2006) investigated the effects of trauma on intimate relationships by conducting qualitative interviews with nine couples, of which one partner had experienced a past traumatic event. They identified a variety of themes including: increased and decreased communication, cohesion/connection, understanding, sexual intimacy problems, symptoms of relationship distress, support from partner, and relationship resources (Goff et al., 2006). Increased communication was a theme present in all interviews, with participants reporting that talking with their partners specifically about their traumatic experiences had a positive effect on general communication in the relationship. Participants also indicated that being able to communicate with their spouse/partner provided them with the greatest support in dealing with the traumatic event (Goff et al., 2006). Interestingly, decreased communication was reported by most participants. Communication within the relationships that was perceived

to be incomplete, unsatisfactory, or lacking was construed by the researchers as creating a feeling of disconnection between couples (Goff et al., 2006).

Intimacy and Serious Illness

Research into the effects of serious illness on intimate relationships has provided a framework for investigating intimacy. Using the interpersonal process model of intimacy originally introduced by Reis and Shaver (1988), Manne et al. (2004) examined relationship intimacy for women who had received a diagnosis of breast cancer and for their partners. The interpersonal process model of intimacy defines intimacy as a process where through self disclosure of relevant personal emotions and information, a person feels understood and cared for because of the partner's response (Manne et al., 2004). The researchers hypothesised that partner responsiveness would mediate the association between self-disclosure and perceived intimacy, and aimed to evaluate whether there were differences in intimacy processes for the patient and her partner. Ninety-eight women and their partners participated in the study. Participants were required to engage in two conversations, one regarding the cancer and one discussion about general issues. Each partner rated his or her perceived self-disclosure, partner-disclosure, partner responsiveness, and perceived intimacy, following each interaction on a 7-point Likert scale. Results of the study showed a strong association between intimacy and perceived partner-responsiveness, indicating that closeness and caring, and understanding and validation, were closely linked for the participants, and was shown to be equally as important in both conversation types. Limitations of this study included the possibility that the life threatening disease may have changed the couples' perception of intimacy. Other factors including design of study,

sample composition, low participation rate, knowledge of co-existing depression, and naturalness of the interactions may all have negative impacts on the results (Manne et al., 2004). While this study highlights the importance of communication and responsiveness in maintaining levels of intimacy, the question of how couples who are faced with communication disorders that reduce levels of responsiveness can sustain this aspect of their intimate relationships, remains.

Research to date, highlights the importance of strong intimate connections in the maintenance of intimate relationships when one partner is inflicted with a disease or other disability. Spousal acceptance and validation is vital for improving feelings of closeness and intimacy (Manne et al., 2004). However, there is little knowledge about the impact on perceptions of intimacy for adults with acquired communication disorders, particularly considering the central importance of communication to interpersonal relationships. While partner-responsiveness is critical, self-disclosure is also crucial to the interpersonal process model of intimacy, which is an aspect that could be severely diminished by the presence of an acquired communication disorder. It is important to develop an understanding of how an acquired communication disorder, resulting in reduced capacity for communication and self-disclosure, can impact an intimate relationship in order to facilitate effective communication and intimacy for couples who are having difficulties.

Communication and Acquired Communication Disorders

Communication is an integral aspect of daily life for most adults and children. We communicate daily with friends, family and strangers, to express our needs and wants, air

our frustrations, and profess our love and devotion (Owens, 2005). It is through interpersonal communication that we interact with others, sharing information about ourselves and our feelings while learning more about the person or people we are communicating with. This type of communication helps build and maintain more personal or intimate relationships (DeVito, 1995).

Communication can be separated into different components of verbal and nonverbal communication. Verbal communication is enhanced through variables such as intonation, volume and pauses, and supplemented by nonverbal communication expressed via body language and facial expressions. In typical communication, these aspects combine to provide effective means of conveying messages (Shames & Anderson, 2002). The natural and precise nature of speech ensures it is generally the preferred means of communicating. However, for many people the thought of being unable to communicate verbally is beyond consideration (Beukelman & Garrett, 1988). Many adults experience a loss of communication ability as the result of disease or trauma. This loss of speech often has serious implications for an individual's social and personal experiences.

Acquired communication disorders occur as the result of a physical, language or cognitive impairment, or a combination of impairments (Beukelman & Garrett, 1988). These injuries or disease processes can seriously impinge on a person's ability to control the mechanisms of speech and language expression (Fried-Oken, Howard, & Stewart, 1991). Each presentation is unique, with the needs and abilities of every individual being distinctive and specific to them, their communication difficulties and requirements.

Acquired Communication Disorders and AAC

Acquired communication disorders result from a range of causes, including degenerative neurological diseases, stroke, or voice disorders due to disease or injury. To date, research has examined the use of AAC by people with a range of acquired communication disorders and has covered many different aspects including types of systems and devices, acceptance of AAC, and purposes of AAC use, as well functional communication abilities and quality of life.

AAC is defined by the American Speech-Language-Hearing Association (ASHA) as:

An area of research, clinical and education practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restriction of persons with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication.
(2005, p.1)

AAC plays an important role in the lives of adults with acquired communication disorders. Caregivers of 26 people with Motor Neurone Disease (MND) were surveyed by Fried-Oken et al. (2006) in order to develop an understanding of the patterns of AAC device use. The results from this study show that the highest levels of AAC use were for the purpose of getting needs met, clarifying needs with caregivers, and giving instructions. The reports of 32% of the caregivers indicated that the persons with MND were using AAC daily to maintain relationships and only a very small amount of 4%, indicated that this was never the case (Fried-Oken et al., 2006). The lowest scores were in the area of social communication especially discussing work, relaying stories, and being romantic. It was discussed that the

reason for these results may be that very few of the people with MND were employed at that time, and a majority of the caregivers were not spouses. It was also hypothesised that romantic gestures between spouses may not require the use of the AAC system or device, rather couples may rely on other methods of communication (Fried-Oken et al., 2006). This study highlights how AAC can benefit the maintenance of relationships for people with MND and their significant others, and also emphasizes how the expression of feelings and intimate messages may adapt as the disease progresses. What research has not investigated is the importance of being able to maintain intimacy, and how the change in expressions of intimacy can impact on the relationships of people with MND.

Additional research into intimacy and MND has focussed on sexuality. In 2004, Wasner, Bold, Vollmer, and Borasio, conducted a study investigating the sexuality of people with MND. Both the person with MND and their partner were asked to complete questionnaires that covered frequency, satisfaction, and interest in sexual contact (Wasner, Bold, Vollmer, & Borasio, 2004). The researchers reported that sexual interest and satisfaction were still relatively high for this population, although lower than before the diagnosis of the disease. The study also identified that many of the reported sexual problems were due to psychosocial aspects. However, while the physical side of intimacy and sexuality was examined, the communication aspect was not addressed in this study. Due to the differing nature of the progression of MND, communication abilities may diminish before physical movement is lost, and the inability to share feelings about psychosocial factors such as self-perception, may have a greater impact on relationship satisfaction than the reduction in physical ability. In order to fully understand the impact

MND has on intimate relationships, discussion about the effect of reduced communication abilities on intimate connections is needed.

Research has examined AAC use by people with aphasia. Johnson, Hough, King, Vos and Jeffs (2008) examined the abilities of several people with aphasia using an AAC device to aid their communication. The study found that people with aphasia improved their communication ability through competent use of AAC devices. The introduction of an AAC device also led to increased participation in daily activities, a finding that was consistent with the International Classification of Functioning Disability and Health (ICF) (Johnson et al., 2008). It was also noted that the caregiver, or communication partner, played a large role in the success of communication using AAC for this group of people and that their level of involvement was directly correlated to the progress that was made by the individual participants. This indicates that support and perseverance by a partner or spouse is beneficial for the acceptance and successful facilitation of communication with AAC for people with Aphasia, and that the use of AAC can be valuable for the maintenance of close relationships. However, further research is needed to develop our understanding of the changes in intimacy as a result of communication using AAC.

Research has also investigated the role of communication in adults with locked-in syndrome. Locked-in syndrome is an acquired communication disorder that reduces communicative abilities to little more than eye-movements. McGann and Paslawski (1991) described an intervention provided for two adults with locked-in syndrome that resulted in successful communication outcomes. The initial communication capabilities of both patients

in the study were limited to yes/no responses via eye movements or blinks. One participant experienced a return of motor movement in one hand nine weeks post onset of the condition. This made it possible for the individual with locked-in syndrome to use a switch connected to a high-tech “SpeechPac” AAC system (McGann & Paslawski, 1991). By 12 months after the onset of locked-in syndrome this individual was consistently using high-tech AAC to communicate in conjunction with some volitional phonation (McGann & Paslawski, 1991). The second participant was also introduced to the “SpeechPac” AAC system once some volitional motor movement returned. Within four weeks of the system being introduced, it was being used to formulate and express more complex communication, and at follow up three years after onset, this person was still using the same system (McGann & Paslawski, 1991)). While these cases show that effective and complex communication is possible for people with locked-in syndrome with the use of AAC, it is not clear what communication needs these people had nor does it discuss the impact using AAC to communicate had on their close relationships.

To date, the majority of the research around laryngectomies and AAC has focussed on communication needs and strategies, AAC intervention and acceptance. In 2000, Carr, Schmidbauer, Majaess and Smith, conducted a study exploring the quality of life (QOL) for people following laryngectomies who were using a variety of communication methods. Sixty-two participants were surveyed and asked to rate their communication and describe any difficulties with communicating. The results indicated there was little difference in QOL for people using an electrolarynx, esophageal speech or a tracheoesophageal puncture (TEP). People using esophageal speech did express less difficulty in sharing emotions than those

using an electrolarynx (Carr, Schmidbauer, Majaess, & Smith, 2000). This study identified areas of concern and difficulty for people following laryngectomy in regards to their communication, but did not address the impact of these communication changes on their main communication partners. In order to fully understand the QOL for this population, consideration of experiences and views of partners would provide much needed information of how this area is affected.

AAC Systems and Devices

AAC can offer a means to communicate when verbal communication is no longer available, and can offer assistance to those inflicted with acquired communication disorders. Adults with an acquired communication disorder can feel incapable of fulfilling their previously held family and societal roles, resulting in the person becoming isolated and withdrawn from friends and family, as they come to terms with their disabilities. However, these real and perceived disabilities can often be reduced or overcome with the introduction of unaided communication in the form of a highly symbolic gesture system, or aided communication in the form of either light, or high-tech augmentative and alternative communication (AAC). The introduction of AAC can allow this population to regain their “voice” and potentially reinstate them into the roles they held before becoming communicatively impaired. Decreasing the communication impairment can aid in restoring feelings of self worth and reducing feelings of isolation and therefore improving overall quality of life (Johnson et al., 2008).

Light-Tech and Unaided AAC Systems

Light-tech AAC refers to any system or non-electronic device that can be used to communicate. Examples of Light-tech AAC include cards, boards, pictures, or even writing and drawing. These types of AAC do not produce any kind of speech, but can allow for more complex messages to be shared (Beukelman, Garrett, & Yorkston, 2007). Un-aided AAC is communication without the use of a physical device or system. This type of AAC includes gestures, eye-movements, sign language or any other strategy that does not rely on a physical object. This type of message exchange is often more specific and can require an experienced communication partner.

High-Tech AAC Systems

High-tech AAC systems are electronic systems that may provide the user with electronically generated speech. High-tech AAC devices may have pre-programmed words and phrases that can be accessed when needed, and can also be used to formulate spontaneous messages by typing out letter by letter or through selection of particular words. High-tech AAC is often less portable than light-tech AAC, although many devices are quite small and can be fitted to wheelchairs or easily carried by hand (Beukelman, Garrett et al., 2007).

While the introduction of technology on top of a traumatic life-changing event could be daunting, adults with acquired communication disorders have an advantage over other potential AAC users. Those who have acquired their disorder later in life are fortunate to have experienced successful unaided communication for the majority of their lives and this

strong grasp of language and literacy provides a solid foundation for the introduction of AAC as a communication support (Beukelman & Yorkston, 1989). However, this strong and reliable background of using normal verbal communication also means that the new mode of communication will be compared to the abilities that the person previously had. On top of the loss and multitude of life changes already encountered, communicating with AAC can often be seen as insufficient to fulfil needs (Beukelman & Yorkston, 1989). In order for AAC to be an effective and comprehensive communication tool that fulfils the user's needs, AAC users, their communication partners and professionals must work together to establish a set-up that works well for the individual, with a store of vocabulary that best fits the users communicative requirements (Beukelman & Garrett, 1988). Considering the importance of communication to the establishment and maintenance of intimate relationships, it is essential research documents the role played by AAC in maintaining or developing relationships.

Contribution of the study

To date, research looking at adults with acquired communication disorders who are using AAC has focussed on device selection, providing functional communication, acceptance and use of AAC, and caregiver support (Beukelman, Fager, Ball, & Dietz, 2007; Johnson et al., 2008). What is missing from the research, is how the use of AAC impacts the personal and social lives of adults with acquired communication disorders (Beukelman, Fager et al., 2007). Research into this area will provide important information about how professionals who specialize in acquired communication disorders can best support individuals using AAC in maintaining their intimate relationships. There is a clear need to

develop our understanding of intimacy and intimate communication for adults using AAC and their partners. This information will provide valuable insight into the needs of adults who use AAC and the strengths and weaknesses of existing AAC systems.

This study explores the experiences of intimacy and intimate communication for adults with acquired communication disorders and their partners. Adults with an acquired communication disorders that currently, or previously required the use of AAC, and their spouses/partners will complete brief surveys and participate in interviews focussing on their AAC use in intimate communication. Examining the experiences of these couples and how, or if, AAC is used in intimate relationships will improve our understanding of the importance of developing AAC systems that allow the users and their significant others the opportunity to express themselves intimately. To date, no study has investigated the experiences of intimacy for adults with acquired communication disorders using AAC. Therefore the aim of this study was to explore the experience of intimacy and intimate communication from the perspectives of adults with acquired communication disorders who use AAC and their partners¹.

¹ For the purposes of this study, the term “partner” is used to refer to a significant other who is a spouse or considered to be a spousal equivalent by the individual with the acquired communication disorder.

METHOD

Qualitative research methods are invaluable for examining perspectives and gathering information from inside the lived experience (Yorkston, Klasner, & Swanson, 2001). Qualitative research takes part in naturalistic settings and allows for findings that are holistic, opening to the possibility of investigating underlying issues and emotions that may be less apparent (Bailey, Parette, Stoner, Angell, & Carroll, 2006). Qualitative research methods are particularly useful for observing and scrutinizing assumptions and theories, and allow for the researcher to examine and report on everyday life using non-numerical data (Ezzy, 2002; Minichiello, Aroni, Timewell, & Alexander, 1990)

A qualitative research approach based on phenomenology was chosen for this study to allow for an in-depth exploration of the lived experience of people's intimacy in relation to AAC and acquired communication disorders from the insider's perspective (Patton, 2002). Phenomenology involves the collection of information regarding a specific experience from a selection of individuals, through a series of interviews around the subject. In phenomenology, it is believed that individuals are the experts in their own realities and therefore, in order to gain a deeper understanding, or make sense of a phenomenon, it is necessary to explore the experiences of those people directly involved and examine how they make sense of what they have, or are experiencing (Patton, 2002).

Participants

Ten participants, consisting of three men and two women with an acquired communication disorder and three female and two male partners participated in the study.

Recruitment

Participants with an acquired communication disorder (ACD) and partner participants were recruited through health support associations and speech-language therapists who worked with people using AAC. Twelve individuals with an ACD and their partners expressed an interest in participating in the study. Six of these dyads did not meet the eligibility criteria for the investigation. One of these dyads initially agreed to participate, but then withdrew because of personal matters. Five participants with an ACD and five partner participants participated in the study.

Inclusion Criteria for Participants with an ACD

For inclusion in the study participants with an ACD were required to:

- a) Be aged 18 years or over, with an ACD;
- b) Be in a current long term relationship with a spouse or partner who was also willing to participate in the study;
- c) Have had experiences using AAC some or all of the time as a mode of communication because of their acquired communication disorder;
- d) Be able to participate in an in-depth interview in English using speech and/or AAC

Inclusion Criteria for Partner Participants

For inclusion in the study partner participants were required to:

- a) Be aged 18 years or over;

- b) Currently be in a long term relationship with a partner who had an acquired communication disorder and who was also willing to participate in the study;
- c) Have had experiences using AAC as a mode of communication some or all of the time with their partner because of their partner's acquired communication disorder;
- d) Be able and willing to participate in an in-depth interview in English.

Sampling

Maximum variation sampling, a type of purposeful sampling, was used in this study. It involves identifying "diverse characteristics of particular interest in constructing the sample to maximise the variation in a small sample" (Patton, 2002).

In this study, sampling was sought for these characteristics: gender (male/female), type of communication disorder (speech/language), and progression of communication disorder (degenerative/nondegenerative). At least one participant who met the criterion for each category was recruited. Participant details with the maximum variation sampling characteristics are presented in Table 1.

Description of the Participants with an ACD

The mean age of the participants with an ACD was 44 years, six months (range 32 – 57 years, SD = 10.13). The length of time since onset of the communication disorder was between one and three years for two of the participants, five to ten years for one, and more than ten years for the other two participants. Two of the participants were using high-tech or electronic AAC devices, two were using, or have used a light-tech aided communication

system, such as an Alphabet Board, as main form of communication, and four were using sign or gesture as one of their main forms of communication.

All participants were in heterosexual relationships and were New Zealand Europeans. Four of these individuals were retired, or no longer working due to the communication disorder, and one was still employed for between 20 and 40 hours per week. For full biographical details of the participants with acquired communication disorders see Table 1.

Pseudonyms were used throughout the study in order to protect the identity of the participants. Identifying data such as occupation was also excluded to protect the participants' identity.

Description of the Partner Participants

Five partner participants, two males and three females, participated in the study. Three partners were married to the participants with an ACD, while two were not. Four partners had been in the relationship with the participants with an ACD for more than ten years and were currently living with them, while one had been in the relationship for about 18 months and was not living with the participant with an ACD at the time of the interview. The mean age of the partners was 49 years, two months (range 37 – 68 years, SD = 12.87). Two partners were in fulltime employment, one partner was semi retired, and two were not in paid employment. Four of the partners identified themselves as New Zealand European and one as English. For full biographical details of the spouses/partners see Table 2.

Table 1: Biographical Details of the Five Adults with Acquired Communication Disorders

Participant*	David	Laura	James	Clive	Deb
Age	38	44	32	57	52
Sex	Male	Female	Male	Male	Female
Ethnicity	NZ European	NZ European	NZ European	NZ European	NZ European
Diagnosis	Motor Neuron Disease	Aphasia resulting from Stroke	Locked-In Syndrome resulting from traumatic head & neck injury	Locked-In Syndrome resulting from brain stem stroke	Tracheal stenosis requiring tracheostomy, causing loss of voice
Spoken Communication	NO	YES	NO	YES	YES (mouthling)
Years Since Onset	1-3	More Than 10	More than 10	1-3	5-10
Length of Relationship (Years)	10-20	More Than 20	Less than 5 (18mths)	More than 20	More than 20
Time spent with Partner per day (hours)	1-3	1-3	5-10 (online)	All day	All day
Types of Communication Used	Electronic – EZ Keys Gesture – Grunting, Head Nods, Facial Expression	Written, Spoken Sign Language Gestures Communication Book	Perspex Eye-Gaze Alphabet Board Email	Alphabet Board Spoken Gestures Email	Electrolarynx Nu-Vois III, Written, Gesture, Spoken (mouthling) Computer
Main Communication with Partner	MSN, Emails, Text Message, Skype Gestures	Spoken, Text Message	Perspex Eye-Gaze Alphabet Board Email	Spoken	Spoken (mouthling) Electrolarynx Nu-Vois III
Employment Status	Retired	Retired	Not Working	Working Part-time	Not Working
Living Arrangements	Living with partner, with full time carers	Living with partner	Living alone, with full time carers	Living with partner, with part time carers	Living with partner
Co-Existing Conditions	N/A	N/A	N/A	N/A	Meniere's Disease

*All names have been changed

Table 2: Biographical Details of the Five Partners/Spouses of Adults with Acquired Communication Disorders

Participant*	Maggie	Steve	Hannah	Janet	Henry
Age	38	48	37	55	68
Sex	Female	Male	Female	Female	Male
Ethnicity	NZ European	NZ European	English	NZ European	NZ European
Marital Status	Wife	Husband	Partner/Girlfriend	Wife	Partner
Partners Diagnosis	Motor Neuron Disease	Aphasia resulting from stroke	Locked-In Syndrome resulting from traumatic head & neck injury	Locked-In Syndrome resulting from brain stem stroke	Tracheal stenosis requiring tracheostomy causing loss of voice
Length of Relationship (Years)	10-20	More than 20	Less than 5 (18mths)	More than 20	More than 20
Time Spent with Partner Per Day (Hours)	1-3	1-3	5-10 (online)	All day	All day
Employment Status	Not in paid employment	Working Fulltime	Working Fulltime	Not in paid employment	Semi retired
Living Arrangements	Living with partner, with full time carers	Living with partner	Living alone, partner has full time carers	Living with partner, with part time carers	Living with partner

*All names have been changed

Procedure

Ethical considerations

Ethical approval was gained from the University of Canterbury Human Ethics Committee prior to recruitment of participants (See Appendix A). The researcher followed recommended practices for obtaining informed consent from the individual with language disorders such as aphasia (Kagen & Kimelman, 1995). In order to ensure that the individual with aphasia understood the consent process, the procedures included using pictographic supports on the consent forms and information sheets (See Appendices C and E). The researcher used these sheets and the support of the individual's partner to verify that the individual understood the process. All other participants were provided with the non-pictorial information sheet and consent form (See Appendices B and D).

Interview Procedure

Data collection involved joint and individual semi-structured interviews with the participants. All participants were offered the opportunity to supplement interviews with e-mail responses to any of the questions from the topic guide (See Appendix F).

Joint Interviews

Four of the five participants with an ACD and their partners participated in a joint semi-structured interview that was conducted in their homes (Minichiello et al., 1990; Taylor & Bogdan, 1998). Because one member of couple 3 resided outside of New Zealand at the time of the study, it was not possible to conduct a joint interview with this dyad. The joint

interviews ranged from 27 to 81 minutes with a mean of 56 minutes (STD= 23.6). The semi-structured interviews involved a conversation guided by open-ended questions from a topic guide about intimacy and intimate communication in relation to AAC use and acquired communication disorders (See Appendix F). All joint interviews were completed in one sitting.

Individual Interviews – Participants with an ACD

Individual semi-structured interviews were conducted with each of the five participants with an ACD in their homes. The partner participant was not present during these interviews. Four of the participants supplemented their individual interviews with a series of e-mail responses to the questions on the topic guide. Two of these participants advised that e-mail was a commonly used AAC system for them due to the nature of their communication problems. A topic guide involving the same questions asked during the joint interviews was used for these interviews (See Appendix F). Length of individual interviews with participants with an ACD ranged from 22 to 26 minutes with a mean of 24 minutes (STD = 2). The researcher followed practices recommended for communicating with individuals with language based communication disorders during the interview with the participant with aphasia. (e.g., encouraging the person to use any mode of communication to respond to questions and verifying participants' communication (Kagen & Kimelman, 1995)).

Individual Interviews with Partner Participants

Three of the five individual interviews with partner participants were conducted in the participants' homes, while one interview was conducted in a quiet private room at the participant's workplace. One interview was conducted over the telephone (due to the participant not residing in New Zealand at the time of the interview) following the practices recommended by Sturges and Hanrahan (2004). The telephone interview was supplemented with a series of seven e-mail responses to the questions on the topic guide. Length of the four individual interviews with partner participants ranged from 16 to 43 minutes, with a mean of all five interviews of 24 minutes (STD = 11). All face-to-face interviews were completed in one session and were conducted without the presence of participants with an ACD.

Digital Video Recordings of Interviews

All face-to-face interviews were recorded using a Panasonic digital video camera (Model – SDR-H250). The same digital video camera was used, without the video recording, to record the telephone conversation. For the telephone conversation the video camera was set up on a table next to the speaker phone and captured the voices of both the researcher and the participant. These recordings were then downloaded to a desktop computer and transcribed verbatim by the researcher based on the conventions of Poland (2001). All supplementary information provided by the participants in relation to the interview topic guide via e-mail was added to the end of their transcripts for analysis. Each typed transcript

was also checked against the original digital recordings of the interviews to ensure accuracy.

This step was also completed by a research assistant.

Data Analysis: Thematic Analysis

Data was analysed using thematic analysis based on the steps proposed by Braun and Clarke (2006). Thematic analysis is an inductive form of analysis for “identifying, analysis and reporting patterns (themes) within data” (Braun & Clarke, 2006).

The researcher began by reading each transcript several times in order to immerse herself in the data and to become familiar with the depth and breadth of the content. During this process the researcher made notes and highlighted areas that were seen to be significant, or reoccurring throughout each transcript.

The researcher then systematically examined the entire data set in order to identify initial codes. Each transcript was given the same treatment and reflection and was examined to the fullest extent in order to extract the individual qualities of the data. Related codes were then collated into potential themes. The themes were then reviewed in relation to the entire data set, with ongoing analysis to refine the specific details of each theme.

The researcher and supervisors reviewed and discussed the potential themes until consensus was reached. During these discussions, themes were considered and examined in relation to the aim of the study. Any differences in judgements between appropriateness of theme or other aspect were discussed and revised as required. At this point, themes were defined and named, with all parties in agreement.

Rigour

A number of strategies were used to enhance the rigour of the study. First, the researcher maintained an audit trail, in which explicit documentation of decisions about the study were recorded and used for reflection. In this study, the audit trail consisted of the maintenance of a detailed reflexive diary in which the researcher recorded thoughts, research decisions, observations, and reflections throughout the study. In order to make sure no data was unintentionally excluded from analysis, repeated readings and discussions of the transcripts were completed by the researcher and a research assistant. No one source of data was considered to be more important than the others. Each transcript was given the same treatment and reflection and was examined to the fullest extent in order to extract the individual qualities of the data. During these discussions, themes were considered and examined in relation to the aim of the study. Discussion between the researcher and supervisors was then undertaken in order to reach consensus. Any differences in judgements between appropriateness of theme or other aspect were discussed and revised as required.

All participants were also invited to view the digital recordings of interviews that they participated in as well as the typed transcriptions from the interviews. As stated in their research information sheets, participants were advised that individual interviews would not be shown to their partner without consent. Three couples requested a copy of the digital video recording of the joint interview, and two of these couples also requested a copy of the individual interviews. These were provided separately on Imation Rewritable CD's along with typed copies of the transcripts. All video and transcribed copies of joint and

individual interviews were provided separately in sealed envelopes in order to maintain confidentiality. Participants could provide feedback on whether their thoughts/behaviours had been accurately represented and were advised that any information would be adjusted accordingly. Participants were also advised that any information in the transcripts would be excluded upon their request. All identifying information was removed from the transcripts. None of the participants requested any changes to the information provided.

Reflexivity

In qualitative research, the researcher is the instrument and is active in both data collection and analysis. This brings the researcher's qualifications and personal experiences under inspection (Patton, 2002). Therefore, it is important to acknowledge and reflect on possible biases that may be present. The researcher is a qualified speech-language therapist with limited experience working with adults with acquired communication disorders, although she did have prior theoretical knowledge about issues or potential difficulties that may be present for this population using AAC.

In order to minimise any possible personal bias, the researcher kept a reflexive journal in which thoughts, observations and reflections were recorded after and between each session. These notes were used by the researcher in preparation for subsequent interviews and were also reflected upon during transcription and the initial stages of data analysis. The recorded notes and observations were particularly important when transcribing some interviews in which the speech of the participant with an ACD was more difficult to comprehend from the digital recording. Any observations recorded by the

researcher that were considered to be more subjective personal reflections were discussed with supervisors.

RESULTS

Eight themes related to the experience of intimacy and intimate communication for adults with an acquired communication disorder using AAC and their partners, emerged from the data. These themes were: effort, importance, time, closeness, adaptation, emotion, identity, and privacy. Each of these themes is discussed below together with examples of the participants' quotations.

Theme 1: Effort

Effort was a key theme in the study. The theme included effort from both communication partners, effort by the communication partners without communication difficulties, and effort by the person with communication disorder. The theme of effort referred to expressions regarding the loss of fluidity in communication, or discussions about any extra lengths that either partner needed to go to in order to maintain their intimate communication. It also involved any difficulties or changes that the couples have had to overcome by changing the way they communicate or the ways partners have made communication easier for the person with an ACD.

Findings from Partner Participants

Comments from partner participants highlighted areas in communication that required extra effort from both themselves and their partners. At least one member from each couple commented on the increased need for effort from both partners when communicating with an AAC system or device, and the impact that this had on the

communication and intimacy within their relationships. For some participants it was a balance between what has been lost and what AAC can provide. Maggie commented:

So [AAC has] brought back more but it loses the banter that you have, that free flowing speech, and the banter and the quick bouncing off ideas, that sort of thing.

Hannah also talked about the difficulty of using AAC in more intimate situations, highlighting the impracticality of some methods of AAC in these circumstances. She also focussed on how the introduction of other methods of communication were necessary and helped maintain a sense of intimacy:

It sometimes gets a little bit frustrating I think for both of us because he wants to [say] something and I have, you have to sort of get the board, I did make him a really small board for us to use when we're together because, cause it was getting in the way a bit ... we mostly communicate through the board but obviously, um, like when we're in bed together he, he used to, he does like, gestures that, with his head, that I recognise for certain things. So it's not just using the board and, and uh, the spelling of words.

Effort on the part of other communication partners was discussed by Steve when he reflected on how communication difficulties impacted on Laura's interactions with others who may not have been as aware of what was required to maintain a conversation. Steve expressed what he considered would be beneficial in Laura's ongoing recovery:

Well it just, it just to communicate, it doesn't matter about her disabilities about her arm or work, I think if she could communicate for longer with people cause once the formalities are over and done with when you see

somebody it's a struggle... it's a struggle for her and it's a struggle for those people, it's not a struggle for me.

Three of the partners talked about the increased effort required on their part in maintaining communication after the onset of the communications difficulties. For some the increased demands that maintaining communication with a partner who is using AAC entails could be challenging, as Maggie discussed:

It's like a long distance phone call when you're stopping and waiting for someone all the time and it becomes very staggered and sometimes it just becomes too hard certainly as the day goes on.

Developing new personal attributes in the light of communication difficulties was seen as a positive side effect of the extra effort required. Henry talked about his personal experiences and how he used what he gained to keep working on his relationship:

[I developed] more tolerance, more patience, more everything really um, because in the past it might not have worked so therefore you know the reasons it hasn't worked you know, um, so you put those aside and keep looking for the positive aspects of the bits you do know that will work so yeah.

Some couples have developed ways to reduce the effort required on the part of the person with the communication disorder. For example, Maggie commented:

There's a lot of guess work that goes on, trying to pre-empt what David might be trying to say and then he will yes or no the answer and elaborate as and where he wants to put the energy into.

Findings from Participants with an ACD

The loss of the ease and spontaneity of communication that exists in most intimate relationships came through strongly during several of the interviews with the participants with an ACD. Deb who uses a hand held electrolarynx after losing her voice summed up the difficulty she had maintaining communication in the most common of situations:

Communication isn't easy you see for us I mean a lot of people talk while they're doing the dishes or talk while they're cooking or talk while they're in the car, while we're in the car it's too noisy for him to hear my voice and when I'm trying to cook I've only got two hands and it just puts extra barriers in communication instead of being easy and flowing it's something we actually put a bit more effort into.

The extra effort and speed required in communication when using an AAC system was frustrating for Clive who found it difficult not being able to:

... Just say anything as soon as the conversation turned to it...

While some couples have found ways to make communicating manageable, Deb expressed how she found the additional effort required on her behalf to be too much:

I stopped communicating really because ... it was just too, it was just easier not to talk, it was too much effort involved ... I don't make the effort I used to, to maintain relationships.

Theme 2: Importance

The theme of importance referred to the re-evaluation of priorities and essential needs after the life changing events of developing an acquired communication disorder, and

included the need to prioritise communication, personal priorities, and relationship loss/gain.

Findings from Partner Participants

Making communication a priority and only discussing the things that were important and crucial came through in several interviews. Henry commented that:

You get rid of all the rubbish, so what you talk about is, tends to be more important and ah, or vital.

For Steve, it was evident that Laura's well-being and recovery have been his number one focus since her stroke 11 years ago. He reflected on the importance of this for him and his relationship with Laura, stating:

She was my priority, I think I made my point pretty well clear and I always, always have ... that's what I was doing to filling in my time instead of being out in the garden and letting her stagnate in front of the TV, I was actually in there playing games, doing things, trying my best while the weeds were growing in the garden.

During some of the interviews, the concepts and loss and gain came across strongly. There was discussion of loss and gain for the partnership as well as for themselves as individuals. Maggie summed up their loss when she explained what intimacy meant for her and David since the diagnosis of MND, describing it as:

Intimacy means for us basically everything we've lost because of [MND] pretty much isn't it? So it is that closeness, it's, it's being able to

communicate, it's being able to touch, it's being able to show facial expressions, and being able to be close to someone without any barriers.

Relationship gain was seen as an important aspect for Maggie and David which was evident when Maggie reflected on how David being at home and having to stop work had opened new opportunities for them as a couple, explaining that:

There's a relationship there that's actually grown because of that that has been lost.

Findings from Participants with an ACD

The aspect of prioritising messages and giving importance to communication in order to preserve energy and avoid wasting time was significant in most interviews. David expressed how with using AAC you have to:

Choose your words carefully ... Intimate conversation still happens but in shorten and to the point.

For some couples, living with a communication disorder helped them prioritise other aspects of their lives and let them refocus on what they felt was truly important. For James, who had only recently begun his relationship with Hannah, his communication disorder and physical disabilities had given him time to re-evaluate his life and relationships, he commented:

I never really talked with my girlfriends before the stroke.....completely different now....thought lots about life after my accident (especially during my 2 years in hospital), what I want from my girlfriend, what makes a relationship healthy – COMMUNICATION, listening, expressing feelings,

MORE COMMUNICATION...life's too short...more mature now, accident
 MAKES you grow up & think about life (what's really
 necessary/important/essential)...

Clive has also re-evaluated his life since his stroke and felt that:

Physical things don't seem so important. Like physical possessions.

Theme 3: Time

The issue of time was identified as a significant concern for most partner participants. The theme of time incorporated time pressures and time saving techniques employed to reduce effort for both partners. It also encompassed the need for special time to be put aside specifically for intimate communication and quality interactions that may not be have been possible otherwise.

Findings from Partner Participants

Some of the couples had made changes to the way they communicated in order to save time as Maggie explained:

You know how there's always that standard joke about married people
 and they finish each other's sentences ... that really came into effect and we
 actually had to tell people this is what we're doing and it's ok to do that ...
 but it just saved a lot of time and hassle.

For Hannah and James who communicated via email due to their long distance relationship, time was very important and played a major role in the way they communicated, as Hannah explained:

On weekends we have, we do more emailing sort of because we have more time ... obviously because he, he's slower at typing than me sometimes his responses aren't as detailed as mine and sometimes he'll, he'll just start a conversation thread and then I'll sort of put more detail in or whatever.

For Steve, not having the time he used to have to spend with Laura came across as a personal struggle when he talked about how:

I've never got the time now... I used to when I was home all the time you know I'd be, I'd be doing exercises on the floor um bits and pieces, but with three hours a day what can you do?

Conversely, having to stop work was seen as being beneficial for increasing the quality time David and Maggie had to spend together and for Maggie had ignited part of their relationship that was missing. She explained:

I'm just in the throes of starting up a business and David had one which had to stop and we talk a lot more because of that because David's come on board and he's got all these fantastic skills that I don't have so we work together as a team, which we always had done in the past but we're a team on a project that I'm now doing so we have a lot more interaction during the day, which is really good.

However, even with the increased time David and Maggie did have together, it was evident that this element was still crucial in their relationship:

It's David's birthday coming up on Friday and he said to me what, I said to him "what do you want for your birthday?" and he typed in "time", as in he wanted time spent with me to just hang out, talk, be together, whatever.

Theme 4: Closeness

The theme of closeness included the aspects of closeness and connection for couples, and physical closeness which had proved more difficult due to co-existing physical disabilities, although was also seen by some as beneficial in developing the emotional connection in their relationship.

Findings from Partner Participants

For those couples who were in relationships before the onset of the communication disorder, most commented on how their experiences through illness and upheaval had strengthened their relationships, although it had been reportedly difficult at times. Steve summed up his feelings about their relationship since Laura's stroke:

We're closer than we ever were um definitely so, definitely we're more intimate than we used to be um probably sexually we're not as much um, as we were but I mean that's, that could be a ah progression through 20 years ... but as far as closeness is concerned it's just getting tighter and tighter really.

Having a long-distance relationship meant James and Hannah had limited physical contact, and didn't have the ability of using other forms of contact in their everyday communication. For Hannah this had been a positive experience, and had highlighted for her, the importance of communication. She said:

The type of communication I have with James is quite different to that I have had in previous relationships ... I think that due to our separation we do tend to talk more, and we are becoming more and more intimate in our

discussions, particularly in relation to the physical side of our relationship, we are definitely very open with each other and completely honest.

Intimacy also encompasses physical closeness, and for some of the couples this had also been impacted by the physical and communication difficulties. After 35 years of marriage, one of the biggest obstacles to intimacy for Janet and Clive was the physical separation that they had to overcome. Janet discussed how this changed intimacy for them:

I knew it was going to be pretty tough but just try to talk to him about, for one thing, we were going to be sleeping in separate beds, and, I mean you can't really, it's not the same sleeping in a single bed and waking and having to cuddle where you have to make an effort to do those things ... And so, sometimes we'd put our beds together so he could hold my hand, or rub my feet or whatever.

Findings from Participants with an ACD

Laura was able to express her take on her connection to Steve simply when she expressed her feelings about him:

Um, soul, soul mate.

Similarly, Clive discussed his feelings and what benefits he saw there had been for their relationship, by saying:

The stroke has probably strengthened our relationship ... it's probably brought us, as I said, closer together, and I'm now more aware of her.

Theme 5: Adaptation

The theme of adaptation encompassed the aspects of changing the method of expressing intimacy, barrier of AAC to intimacy, and non-verbal communication.

Adaptation included comments and discussions that centred on adapting communication methods in order to maintain effective and efficient communication, and also unsuccessful changes or difficulty with communication due to the inability to adapt.

Findings from Partner Participants

For some of the couples AAC systems and devices created barriers to intimacy and changed the dynamics of intimate communication in their relationship. For Henry the reduction of spontaneity in expressing a message played a big role in the fluidity of his communication with Deb:

You think of something that you want to say to your partner like Deb and then, you store up a number of questions whereas normal ah, a couple don't do that it automatically comes out and it's solved at the time or you know, talked about or debated or whatever the case may be um, for us I think that it you know yes you build up a system of questions and then you can't find the voice, voice first, person second.

Henry also discussed the other side of AAC and how the introduction of the electrolarynx had been incredibly beneficial and had stripped away some of the barriers in their communication. He summed up his feelings about the device by saying:

The point is that this little electrolarynx is the best thing that ever came about because you know, it was really frustrating for me before that and

it's much easier for me now even though I laugh and I make as though it, there are problems about it, and I do swear and curse because she'll leave it in the car and the phone goes or whatever, and, and it becomes a bloody curse sometimes, it's still the best invention out.

Even with physical and communication difficulties, David and Maggie had maintained their connection by incorporating non-verbal communication as Maggie explained:

Probably like any other couple you just have, that comfort that that you know like any relationships you know somebody so well in fact you could almost talk through your eyes in fact because you know somebody that well and yes and a no or a (rolls eyes to indicate disbelief) couldn't believe that or whatever.

Findings from Participants with an ACD

With the removal of natural speech as an option for communicating intimacy, couples have had to make changes to how they express themselves to each other. David explained how the adaptations hadn't taken away from their intimate communication:

[We] just [express ourselves] differently ... quality is still the same it's just different way you put it across.

In contrast, the need to change methods of communication had a negative impact on other couples intimacy, with the new methods not working sufficiently to replace natural speech. Deb talked about her experiences and how she felt her communication was still not adequate in some areas. She shared:

There is a way of communicating with not using words and that's missing in our sex life now, and I think that's affected [Henry's] sexual response

cause [he's] not getting messages from me that I'm having a really good time.

Exclusion of significant intimate communications and physical interactions was also a significant factor for Deb who explained:

The biggest barrier that I find in that, is that I can't whisper sweet nothings in his ear anymore ... there's a whole dimension of our sex life that's disappeared by number one, no longer being able to whisper sweet nothings ... [the electrolarynx] really doesn't communicate in the bedroom as a device for intimacy so we don't take it to bed for that purpose.

David also discussed the barriers of using AAC and how it had excluded crucial aspects of their intimate communication. He described how:

We communicate through technology which often prohibits quick banter and free flowing witty conversation.

David also talked about how he and Maggie had to make changes but still retained their intimate connection when he stated:

Intimacy goes out the door to some degree, but is replaced by the look in the eyes.

Theme 6: Emotion

Both negative and positive emotions came through strongly for the majority of the participants in this study. Within the theme of emotion, the negative aspects of arguing, frustration and the meaning of intimacy were most significant.

Findings from Partner Participants

In some of the interviews, the ability to express unhappiness or disagreement through arguing was indicated as being an important part of their relationship, and something that they still were able to do. Maggie summed up how arguing for her and David was still part of their communication, but had altered since the changes to David's communication:

Arguing is very mature we still argue ... but there's no, no chance of walking out and storming out because no one can chase you if that was ... but I would argue and then I would stand and wait for David to respond ... you can be really fired up and say something and then you think right, wait, wait, wait, wait, wait, wait ... it's just the sitting on the fence thing, I don't know you just sort of blank out and wait and then, you're back in again.

Feelings of frustration were strong for every couple throughout the interviews. For some the frustration was due to the lack of communication, Henry expressed how he felt, saying:

My mistakes are, have been in the past frustration through not being able to communicate at the time, and um, and that's a learning exercise and we're all different and some of us are good at it and some of us aren't.

Hannah talked about the difficulty of incorporating an AAC system or device into everyday situations:

I think um because of, because of his um disability and having to use the board it's sometimes a bit frustrating for him and it's also quite difficult if he sort of like when we're in bed and he wants to say something and I have to get the board and it can be quite awkward.

For Janet, feelings about intimacy and her relationship with Clive were put simply when she expressed:

I think [intimacy is] just caring for someone and being able to talk, to talk to them, and um, sort of see how they're feeling, and saying how you feel, yeah.

And Henry's view was in agreement, saying:

[Intimacy is] quality of ah, communication really in depth, quality, coupled with emotions and feelings and that sort of thing.

Findings from Participants with an ACD

When asked about communicating with Steve, Laura expressed the emotions she felt when she wasn't able to communicate:

Um I, talking no talking, ah, ah frustrated, yeah frustrated.

For others, the frustration came from the extra demands of using AAC. Deb described the frustration her device caused in her relationship with Henry, stating:

So although the electrolarynx allowed communication, it was incredibly confronting for Henry, it was extraordinarily frustrating if I couldn't find it or if I put it down, or I tried to communicate with him in any other way, cause the only communication was, in his opinion, to use the electrolarynx.

Emotions were also a strong component of how the participants described what intimacy meant to them, both as a couple and as individuals. David described intimacy as:

Personal conversation between a couple... Touch and feelings are included as well.

Theme 7: Identity

The theme of identity was made up from statements by participants about the loss or change to identity due to the onset of the communication disorder and the use of an AAC system or device. The loss of identity or sense of self came from both the participants with an ACD and from the partner participants who expressed the loss of an important part of their partner.

Findings from Partner Participants

Maggie discussed the depersonalisation of the AAC device David uses, saying:

I think it would have been nicer to have had David's voice on it ... David could have had his voice right up till the end so it might not have been needed, but, it would have been really nice to have at least some key phrase.

The aspect of depersonalisation and how using an AAC device had meant David could no longer fulfil all aspects of his role as a father were discussed when Maggie shared:

...yesterday we were given a voucher for [our daughter] and David to go and get a teddy bear made and you can do a voice recording and you go into a booth and he could say something like "goodnight Suzy" so when she's cuddling the bear at night she can squeeze it but he can't do that so you have to look outside the box and think what can we do.

Findings from Participants with an ACD

Deb summed up her feelings on losing her voice, expressing:

It's amazing how a voice distinguishing is not just our personality and our persona but our sex and it's yeah, it's weird how our voices are so magical and we take them for granted and we don't even appreciate how magical and complex and interesting and unique they are so, yeah oh to have it all.

Theme 8: Privacy

For the three couples who were experiencing severe physical disabilities on top of the communication disorders, the impact of having carers in their homes had been challenging within itself. The theme of privacy encompassed the feelings of participants who had full or part-time carers, and how this had impacted on their intimate communication.

Findings from Partner Participants

Hannah, who due to their long-distance relationship had only been able to spend a short amount of time with James, shared their experience saying:

We didn't really talk about much in [the carers] presence and I think conversation was quite stunted and at a bare minimum, with them there. James is very personal and doesn't really appreciate other people, particularly carers, knowing his business ... it did often feel like an invasion of our privacy.

The other female partner participants also discussed the impact that carers had on their relationships and ability to maintain a sense of normality. Maggie and David's experience

echoed that of Hannah and James, and Maggie shared how the presence of others hampered her ability to communicate with David by saying how:

Now our stumbling block really is the lack of privacy we have ... I really want to tell David about [something] but there'll be somebody here and just, and sometimes you just want that privacy.

Janet also expressed her thoughts on the carers, and the impact that having other people present in their home had had on their relationship. She summed it up by saying:

I don't really think communication has had too much effect on us as much as possibly having carers in the house ... yeah I think, just having people invading your home.

DISCUSSION

The aim of this study was to explore the experiences of intimacy for adults with acquired communication disorders using AAC and their partners. The study revealed eight themes; effort, importance, time, closeness, adaptation, emotion, identity and privacy.

Effort

The couples who participated in this study all acknowledged the increased effort required in their communication since the onset of communication difficulties. The theme of effort was surmised from comments or statements that reflected on the loss of fluidity in communication, or discussions about any extra lengths that either partner needed to go to in order to maintain their intimate communication. The theme of effort consisted of the aspects; effort from both communication partners, effort by communication partners without communication disorders, and effort by person with communication disorder.

Being able to freely communicate with a spouse or partner is perhaps the greatest support in dealing with a traumatic event (Goff et al., 2006). Communication that was perceived to be incomplete or lacking was interpreted by the researchers as creating feelings of disconnection between the couples. For some of the participants in this study, the extra effort required by either partner in order to maintain effective communication was reported at times to be “too hard” or “too much effort”. These responses indicate that elements of communication within the couple’s relationships could be perceived as being incomplete or lacking and therefore could lead to feelings of detachment or separation.

Importance

The sudden onset of a communication disorder can result in the re-prioritisation of goals or ambitions. For some people, an acquired disability can make them become reclusive and shut off from activities and people they once considered important. For others it may increase their ambitions to fulfil goals or dreams that they felt unachievable before the life changing event. In the current study, the theme of importance included the aspects of; prioritising communication, personal priorities, and relationship loss/gain.

Most of the participants in the current study discussed how having an acquired communication disorder or being in an intimate relationship with someone with an acquired communication disorder, has made them re-evaluate what they consider to be important. The information chosen to discuss with partners has become more significant for most participants. Several participants explained how it is essential to eliminate the unimportant information that they may have previously shared, in order to save energy and time for what really matters. The re-evaluation of what is really most important in life was also discussed with participants explaining communication and a healthy relationship has now taken precedence over physical possessions and material things.

Relationship loss and gain were expressed as the consequence of the onset of communication disorders and co-existing physical disabilities. Most poignantly when asked about the meaning of intimacy, Maggie shared her feelings about her relationship and the loss that she and David have experienced since receiving the diagnosis of MND and the subsequent changes they have experienced.

Intimacy means for us basically everything we've lost because of [MND] pretty much isn't it? So it is that closeness, it's, it's being able to communicate, it's being able to touch, it's being able to show facial expressions, and being able to be close to someone without any barriers.

This comment alone highlights the devastating impact of an acquired communication disorder on an intimate relationship. Acting in the best interests of this population, it is crucial to address the importance of professionals being able to provide couples with ways to minimise the impact of sudden, life-altering changes on interpersonal and intimate interactions.

Time

Other life commitments such as work and family can also impact on the quality of interactions for couples. The added hurdles of physical and communication difficulties can reduce the opportunity for quality time. For others, the extra time required for communicating with AAC changes their ability to communicate and often in-depth communication needs to be placed on hold until more time is available.

One of the downfalls of needing more time to communicate is the reduction of sharing information or problems that previously would have been discussed, debated and resolved together as a couple. Becoming independent in decision-making may be seen by some as a positive personal achievement, but could also be seen as the separation of two people who previously functioned as a single entity. One couple in the present study discussed how the communication disorder had started to break apart the connection they

had. Refocusing and finding a project of mutual interest that they could work on together had brought them back to the point where they again saw themselves as the “team” they had previously been. These results are consistent with Miller et al. (2009), who described the interdependence in intimate relationships. Identifying as a couple rather than individuals is key to differentiating an intimate relationship from other relationships.

Closeness

The theme of closeness encompassed the aspects of; closeness and connection, and physical closeness, with most of the participants discussing only positive aspects in relation to these themes.

For several of the couples, the changes and experiences they have had to cope with since acquiring communication disorders have been attributed to the strengthening of their relationships. These results support the discussion by Mashek and Aron (2004), who talked about how deep understanding and knowledge of the other person strengthens intimate interactions and relationships.

The results from the current study are comparable to the results of the research conducted by Yorgason et al. (2007), which also indicated that couples who were able to accept changes to their relationship due to acquired communication disorders, were more likely to find their relationships strengthened by the experience. Similarly, Anderson and Noble (2005), reported that couples able to accept the communication disorder had higher levels of relationship satisfaction. The results from these studies link to the findings from the

current study, indicating that helping couples come to terms with the communication disorder is beneficial in facilitating strong, supportive intimate relationships.

Physical closeness was also highlighted by seven of the participants and is an important part of intimacy for many couples. The physical separation resulting from the acquired disabilities had a significant impact on the perceptions of intimacy for one couple. As indicated by participants, reduction in the ability to spend quality time with a spouse due to physical disabilities could result in reduced opportunities for intimate communication. For many couples, a majority of communication, especially intimate communication, may be shared at night, as this may be the only time they are alone. Couples who experience physical separation may require extra counselling and support to minimise the impact on their relationship.

Adaptation

Living with an acquired communication disorder and maintaining meaningful communication in intimate relationships requires adaptations. Communicating with AAC requires a great deal of adjustment as the method and quantity of communication change dramatically. Co-existing physical disabilities that result in changes to employment or living arrangements could also require adaptation for both partners.

For the participants in this study, the theme of adaptation included the aspects of; changed method of expressing intimacy, barrier of AAC to intimacy and non-verbal communication. Participants discussed the changes they have made in order to retain

intimacy, and for some, adapted communication when using AAC is still not adequate to convey intimate messages.

The findings from this study are similar to Hetu et al.'s (1993) reports of tension and adaptation problems following the onset of communication difficulties, which has been indicated to impact the communication in intimate relationships. Difficulties with adapting to the hearing loss were discussed by Hetu et al. as being stressful for both people in the relationship. For the person with the communication disorder, accepting the changes in their communication abilities and adapting methods as well as messages can be stressful especially after a lifetime of unimpeded communication. For the partner, having to change the way they communicate with their loved one as well dealing with the other life changes that may be present after a traumatic accident, illness, or the diagnosis of a disease, could be incredibly confronting and cause tension or anxiety. Similarly, the current participants talked about how communicating with AAC has meant they have had to adapt the way they share information with each other. Couples also indicated these adaptations contributed to stress in their relationships.

For three of the couples, successful adaptation has seen an increase in non-verbal communication to replace some previous verbal communication. Developing strong non-verbal communication is important for people who are using AAC as devices and systems may not always be the most efficient and effective method of expressing a feeling or sharing a moment. Replacing intimate words with non-verbal expressions has meant that intimate connections have been maintained for some couples, lessening the stress and tension

involved in adapting to an acquired communication disorder. This is consistent with Fried-Oken et al. (2006), who hypothesised that AAC systems or devices may not be used by couples when expressing romantic gestures, and instead other methods may be adopted as the disease progresses. As David expressed in the current study, “intimacy goes out the door to some degree, but is replaced by the look in the eyes”. This comment indicates that while light and high-tech AAC systems are useful for delivering some messages, unaided non-verbal communication and gestures are quicker and more meaningful when expressing intimacy.

Emotion

The theme of emotion was expressed strongly in all interviews. Emotion encompasses all facets of both positive and negative emotion. The aspects of emotion that were most apparent were; arguing, frustration, and the meaning of intimacy, with all participants commenting on at least one of these areas.

Experiencing a communication disorder with or without co-existing physical disabilities can be distressing for not only the person directly involved, but all those people connected to them. The upheaval of life can lead to feelings of grief, frustration and despair as aspects of personality and identity are lost or irrevocably changed. The participants discussed feelings of frustration due to not being able to communicate or because of the demands of using AAC. This aspect was highlighted by one of the couples as being a monumental part of their communication breakdown. For that couple, identifying the cause of the frustration and taking steps to eliminate, or reduce it, helped them regain an element

of intimate communication that had been lost. It is indicated that in order to reduce, or potentially eliminate this frustration, additional methods of communication must be included within a person's AAC system. Professionals providing AAC systems must not view an AAC device separately from a person's communication system (Beukelman & Mirenda, 2005). Gestures and non-verbal communication are both portable and instantaneous, and while messages may not be as complex when delivered via these means, it may be a more efficient way of quickly sharing an intimate moment or crucial message. AAC systems should also include light-tech or unaided alternatives.

Identity

It is common for people with acquired communication disorders to feel a loss of identity or sense of self (Beukelman, Yorkston, & Reichle, 2000). Natural speech encompasses more than just ease of communication, it identifies people as individuals and is a major part of who we are. While technology and AAC can replace some aspects of communication others aspects are lost.

Loss or change of identity was indicated by some of the participants as a facet of their relationship that has been altered as a result of their communication difficulties and use of an AAC system. Both couples who used speech generating devices discussed how their loss of voice had impacted on their sense of identity and had how they felt others perceived them. For one partner the idea of voice banking was discussed with some regret. Voice banking is the process of pre-recording and storing messages that have particular meaning or significance in advance of losing voice (Beukelman, Garrett et al., 2007). The process of

voice banking means that the individual's voice is stored which can provide a meaningful and personal connection for the message recipient (Beukelman, Garrett et al., 2007).

However, the unknown consequences of MND meant that the communication implications of the disease may not have fully eventuated until much later in the progression of the disease. Although dealing with the unknown aspects of a progressive communication disorder may be overwhelming for couples already coping with many changes, professionals need to be aware of preparing clients for all possible eventualities. This may include confronting the issue of voice banking with a view to ensure future AAC systems are highly personalised.

Maintaining a sense of self is important for anyone who faces a dramatic life change. For those people who acquire a communication disorder, the loss of identity or perceived loss of role within society can be overwhelming and could lead to feelings of depression, or result in isolation and withdrawal from society. Similarly, a partner who has maintained a specific role within a relationship could find themselves faced with having to step into a role they have never experienced. For example, income earner or taking on personal care duties. The loss of a familiar support system can be as devastating as the loss of communicative function. On top of changes to life style and the loss of intimate support, partners must deal with changed communication and supporting their partner as they adapt to new methods of communication.

Privacy

Privacy was expressed as an important aspect of participants' ability to maintain intimacy in their relationships. For couples who physical disability was a factor in their lives, the presence of full or part-time carers in their homes was seen as having a negative impact on their relationships and their ability to communicate fully with each other. The presence of carers led to one couple minimising their communication in order to avoid others outside their relationship being privy to their personal business and intimate communication. This particular couple are in a long distance relationship but have had two short periods of time together during their relationship. Because of the long distance relationship the time this couple has been able to spend together has been valuable. The presence of full time carers was discussed as being an invasion of their privacy and negatively impacted on the limited time they had to spend together.

The negative impact of being unable to communicate effectively or spontaneously with a partner correlates with the findings reported by Manne et al. (2004). Using an interpersonal process model of intimacy, Manne et al. found that partner responsiveness to self disclosures was strongly linked to perceptions of intimacy. For the couples in this study who believe their freedom to express feelings, or discuss important aspects of their lives was limited due to the presence of carers, the perceived lack of privacy has greatly impacted communication. As there may be reduced opportunity for self disclosure, the responses from their partner that would foster feelings of caring and understanding are also reduced, negatively impacting on perceptions of intimacy. When organising care for this population, professionals must support couples allowing them to spend time together without

unwanted outsiders. Although carers are crucial for some couples, especially when physical disabilities are also present, the freedom to relax and communicate candidly or share personal moments is also important to the well-being of relationships.

Clinical Implications

The findings from this study highlight several implications for professionals working with adults with acquired communication disorders who may use AAC and their partners. All of the participants in this study talked about areas that impacted on their ability to maintain intimacy within their relationships. While the factors were different for each couple, some general areas emerged as being concerns for all participants.

The extra effort required to maintain intimate communication when using AAC was reported by all participants. Professionals working with this population should therefore consider intimate communication when setting up AAC communication systems. More focus may be required on light-tech and unaided AAC such as facial expressions and gesture, or pre-programming high-tech devices to include personal and relevant messages that support intimacy. Professionals should be aware of the many demands on partners of people with communication difficulties, including the added burden learning new ways of communicating. These added responsibilities may result in intimacy being pushed aside while the relationship changes from intimate to one of patient and caregiver. It is important that intimacy is supported as studies have indicated that strong intimate relationships result in better quality of life and better overall outcomes for couples.

Communicating via an AAC system or device is more time consuming than natural speech. Therefore professionals must identify ways to reduce the frustration and difficulty experienced by people using AAC. Providing strategies that may reduce the time taken to produce a message or respond to a question or comment will help couples communicate more efficiently. Professionals should also be aware of other responsibilities that could introduce time constraints. One partner working full-time or even two jobs in order to support the family when the other is no longer able to contribute to the household income, may result in reduced time for intimacy and time spent together. Professionals could provide suggestions or strategies to help couples in this situation organise their time, or alternatively provide couples with access to organisations that may be able to help in some areas.

For the participants with physical disabilities in conjunction to communication disorders, privacy was a major issue. While all of these participants recognised the importance and benefit of having carers to help with daily needs, they felt that having the presence of others in their homes negatively impacted on their time to be alone as a couple. It is important for professionals to understand couples need for privacy and work with them to organise a balance which would provide time to be alone as a couple. For many people taking on the role of carer for a spouse may not be a possibility especially if physical difficulties exist for both partners, or if one partner needs to be working outside of the home in order to support the family. However, it may be important for professionals to discuss with couples the possible impact carers being present on a full or part time basis can have on their relationships and how they could minimise this. At the same time, carers should be

made aware of the privacy needs of clients and should be encouraged to limit their involvement in personal affairs that fall outside of their caregivers' role.

Both previous research and findings from the current study indicate that couples with strong relationships have higher levels of intimacy even when one partner has a communication disorder or disability. It is important for professionals to discuss the importance of maintaining a strong relationship and have the ability to make suggestions to couples for how they can most effectively preserve this aspect. Couples need to be encouraged to continue to express themselves intimately and share their feelings with each other as it is through self disclosure and partner responsiveness that intimate connections are maintained. AAC devices can be of limited use during intimate communications. Couples may need to be provided with suggestions for alternative methods or ways to express themselves intimately. Professionals may require more training in counselling or seek greater access to multidisciplinary teams in order to incorporate a holistic approach to therapy.

Limitations

The study has some limitations that need to be acknowledged. The study only involved five couples. Ideally, future research could involve a larger sample of participants to provide a wider variation of experiences in order to increase understanding of this phenomenon. The study is also limited by the participants who volunteered to contribute. Even though some of the couples had experienced difficulties in their relationships due to communication and other aspects of intimacy, they were generally in strong, committed,

and successfully intimate relationships. While the data collected from these respondents may not have provided an accurate overall picture of what intimacy and intimate communication is like for all people with an ACD using AAC and their partners, this could also be looked at as being beneficial for other couples in this population. Hopefully, this study could be used as an example for those people in similar situations who are struggling with intimacy and intimate communication, and may feel that that aspect of the relationship is no longer possible or suitable given the changes to their situations. Finally, the fact that some couples were not using AAC on a regular basis for their intimate communication could also be considered a limitation to this study. However, this could also be viewed as a strength in that it highlights how unaided AAC is essential to ongoing intimate communication.

Directions for Future Research

Several areas for future research have emerged from this study. It was noted during the recruitment of participants that there were limited people who were identified as meeting the eligibility criteria for this study. AAC is a beneficial and highly effective way for people with acquired communication disorders to communicate not only with their close family members and friends, but also with other people in wider society and it assists in facilitating the preservation of societal roles (Beukelman & Mirenda, 2005). Research into the reasons why more people with acquired communication disorders were not using AAC could open up opportunities for more people to retain communication capabilities. Alternatively, identifying what happens to clients and patients after receiving therapy services for acquired communication disorders once they are deemed recovered, or no

longer eligible for service, would be beneficial in order to identify if further follow up is required. Finally, more research into intimacy and intimate communication for people with ACD is warranted as it appears this aspect of communication overlooked with an emphasis on functional needs-based communication.

Conclusion

Intimacy and intimate communication are important aspects in the relationships of adults with acquired communication disorders who use AAC and their partners, and can be difficult to maintain when AAC is required to communicate. The strain of an acquired communication disorder, with or without a co-existing physical disability, can be difficult for couples. Being able to maintain a close and intimate relationship could make the difference in recovery and quality of life after the onset of a traumatic life changing disease or illness. It is imperative that professionals are aware of the importance of facilitating intimacy and intimate communication, not only for the person with the acquired communication disorder, but also for their partner, especially when AAC is used. Providing the support and means necessary for couples to preserve this aspect of their relationships requires dedication and commitment, and for professionals to work closely with couples to ensure they are able to use AAC to communicate in the most effective and efficient manner. This study has identified a number of important areas that professionals need to consider in order to facilitate successful intimacy and intimate communication for adults with acquired communication disorders who use AAC and for their partners. It is the hope that through this research, more couples will be able to use AAC to regain and maintain effective and

fulfilling intimate relationships similar to what they experienced before the onset of the communication difficulties.

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APPENDICES

Appendix A – Human Ethics Committee Approval

Ref: HEC 2009/85

16 July 2009

Angela Leigh
Department of Communication Disorders
UNIVERSITY OF CANTERBURY

Dear Angela

The Human Ethics Committee advises that your research proposal “The role of AAC (augmentative and alternative communication) in intimacy for adults with acquired communication disorders” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 8 July 2009.

Best wishes for your project.

Yours sincerely

Dr Michael Grimshaw
Chair, Human Ethics Committee

Appendix B – General Information Sheet

Angela Leigh
c/o Department of Communication Disorders
University of Canterbury
Private Bag 4800
Christchurch

Department of Communication Disorders University of Canterbury

Information

You are invited to participate as a subject in the research project “The Role of AAC in Intimacy for Adults with Acquired Communication Disorders”.

The aim of this project is to explore the role Augmentative and Alternative Communication (AAC) plays in intimacy for adults with acquired communication disorders. The study will find out about the different ways you communicate and how you communicate with your spouse/partner. It will also explore how you use different methods of communication in intimacy and intimate communication with your spouse/partner.

Your involvement in this project will require you to:

- Participate in two interviews, one with your partner/spouse and an individual interview.
- Each interview is estimated to take between 60 and 90 minutes.
- The interviews will be conducted according to your availability, either in one session or over multiple sessions.
- The interviews will focus on intimacy and intimate communication in the relationship with your partner/spouse since the onset of your/your partners communication difficulties.
- The interviews will also explore the use of the AAC system and the role it plays in intimacy/intimate communication with your partner.
- Each interview will be videotaped. The video will be analysed to provide an accurate transcription of the interviews.
- You have the right to review the video or any transcripts of the interviews.
- During the interviews, if you become upset or have feelings of discomfort or fatigue, you can stop the interview.
- You have the right to withdraw from the study at any time, including withdrawal of any information provided.
- Withdrawal from the study will not affect your access to services from the University of Canterbury’s Department of Communication Disorders, at this time or in the future.

A qualified Speech and Language Therapist will be responsible for conducting and videoing the interviews and analysing any data gathered.

Provisions will be made if you wish to have a support person or family member present during the interviews.

The results of the study may be published, but you will not be identified. To ensure anonymity and confidentiality, codes will be used in place of identifying names throughout the research process, and any data collected will be stored in a locked filing cabinet in the researchers' office at Canterbury University. Angela Leigh, Dr. Dean Sutherland and Dr. Tami Howe are the only persons with authorized access to identifying information. A research assistant may be employed to transcribe the interviews. They will sign a confidentiality agreement and will not have access to identifying information.

The information collected may be required for use in future research. The information will only be used with your consent.

All information collected during the study will be kept by the Department of Communication Disorders for a period of five years, after which it will be destroyed.

This study is for research purpose only. Participants should not expect to gain any therapeutic benefit from participating in this study. The interviews in no way constitute any form of treatment.

The study is being carried out as a requirement for the degree of Masters of Speech and Language Therapy, by Angela Leigh, under the supervision of Dr. Dean Sutherland, who can be contacted at 03 364 2987 ext 7176, and Dr. Tami Howe, who can be contacted at 03 364 2987 ext. 3619. They will be pleased to discuss any concerns you may have about participation in the project.

The study has been reviewed **and approved** by the University of Canterbury Human Ethics Committee.

Angela Leigh
Masters Student
Department of Communication Disorders
University of Canterbury
Ph: 03 364 2987 ext. 7603
Email: ale51@student.canterbury.ac.nz

Appendix C – Information Sheet for Participants with Aphasia

Information Sheet for Participants with Aphasia

Title of Study: The Role of Augmentative and Alternative Communication in Intimacy for Adults with Acquired Communication Disorders

Investigators:



Angela Leigh
Masters Student
Department of Communication Disorders
University of Canterbury



Dr. Dean Sutherland
Lecturer
Health Sciences
University of Canterbury



Dr. Tami Howe
Lecturer
Department of Communication Disorders
University of Canterbury

What is this study about?

- I want to learn about the different ways you communicate
- I want to learn about how you **communicate with your spouse/partner**
- I want to learn about how you use different methods of communication in **intimacy** and **intimate communication** with your **spouse/partner**
- This is about **your** experiences

What do I need to do?

- Take part in **two interviews**; one with your spouse/partner, and an individual interview



- The interviews will take between **60 and 90 minutes**



- If needed the interviews can be done over **several sessions**

Session 1

Session 2

Session 3

- We will talk about intimacy and intimate communication in your relationship with your spouse/partner before and since the onset of your/your partners communication difficulties



- We will talk about the use of your communication system and the role it plays in intimacy/intimate communication with your partner.



- Each interview will be videotaped. The video will be used to provide an accurate transcription of the interviews.



- You have the right to review the video or any transcripts made of the interviews.

- During the interviews, if you become upset or have feelings of discomfort or fatigue, you can **stop** the interview.



- You have the right to **withdraw** from the study at **any time**, including withdrawing of any information provided.



- Withdrawal from the study will **NOT** affect your access to services from the University of Canterbury's Department of Communication Disorders, at this time or in the future.
- You may have a support person or family member present during the interviews.



A qualified Speech and language Therapist will be responsible for conducting the interviews and analysing any data gathered

What will happen to the information I give?

- The study may be **published**, but you will **NOT** be identified. To ensure confidentiality, codes will be used in place of names throughout the research process.
- The information will be stored in a locked filing cabinet in the researcher's office at The University of Canterbury.



- Only Angela Leigh, Dr. Dean Sutherland, and Dr. Tami Howe are the only persons with authorized access to identifying information.
- A research assistant may be employed to transcribe the interviews. They will sign a confidentiality agreement and will not have access to identifying information.
- Information collected may be used for future research, with your consent.
- Information collected will be kept by the Department of communication Disorders for **five years**, then it will be destroyed

Will this study help me?

- This study is for **research** purposes only.
- You should **NOT** expect to gain any therapeutic benefit from participating in this study.
- The interviews **DO NOT** constitute any form of therapy.

Why is this study being done?

- This study is being carried out, by Angela Leigh, as a requirement for the degree of Masters of Speech and Language Therapy.

What if I want more information?

- You can contact any of the investigators if you would like more information.



Angela Leigh
Masters Student
Department of Communication Disorders
University of Canterbury
Ph: 03 364 2987 ext. 7603
Email: ale51@student.canterbury.ac.nz



Dr. Dean Sutherland
Lecturer
Health Sciences
University of Canterbury
Ph: 03 364 2987 ext 7176
Email: dean.sutherland@canterbury.ac.nz



Dr. Tami Howe
Lecturer
Department of Communication Disorders
University of Canterbury
Ph: 03 364 2987 ext 3619
Email: tami.howe@canterbury.ac.nz

Who has approved this research?

- This study has been reviewed and approved by the University of Canterbury's **Human Ethics Committee**.

Appendix D – General Consent Form

Angela Leigh

Department of Communication Disorders
University of Canterbury
Private Bag 4800
Christchurch

5 June 2009

Consent Form

The Role of AAC in Intimacy for Adults with Acquired Communication Disorders

I have read and understood the description of the above-named study. On this basis, I agree to participate in the study, and I consent to publication of the results of the study with the understanding that I will not be identified.

I understand that this study is for research purposes. I understand that this study is NOT therapy. The procedures do not constitute any form of therapy.

I consent to being videoed during the interviews, and understand that information collected from the video will be used for the purposes of the study.

I understand that I have the right to review any video recordings or transcriptions of the interviews I participate in.

I understand that a research assistant may be employed to transcribe the interviews. I understand that the research assistant will sign a confidentiality agreement and will not have access to full identifying information.

I consent to the information gathered being made available for future research if required.

I understand that information gathered during the study will be kept by the Department of Communication Disorders for a period of five years, after which it will be destroyed.

I understand also that I may at any time withdraw from the project, including withdrawing of any information I have provided.

I understand that withdrawal from the study will NOT affect my access to services from The University of Canterbury's Department of Communication Disorders, at this time or in the future.

I note that the study has been reviewed ***and approved*** by the University of Canterbury Human Ethics Committee.

NAME (please print):

Signature:

Date:

Appendix E – Consent Form for Participants with Aphasia

Angela Leigh

Department of Communication Disorders
University of Canterbury
Private Bag 4800
Christchurch

5 June 2009

Consent Form for Participants with Aphasia

Title of Study: The Role of Augmentative and Alternative Communication in Intimacy for Adults with Acquired Communication Disorders

I understand:

- I do not have to participate. It is **my choice**.
- The study **may** be published, but I will **NOT** be identified.
- The study is for **research** purposes.
- The study is **NOT** therapy.
- The interviews will be **videoed**.
- I can **review** the video or any transcripts made of the interviews.
- A **research assistant** may assist in transcribing the interviews. They will sign a **confidentiality agreement** and will not have access to my details.
- The information may be used for **future research**, with my consent.
- The information will be kept for by the Department of Communication Disorders for **five years**, after that it will be destroyed.
- I can **stop** the research and **withdraw** from the study at any time.

The information about this study, as presented in the information sheet, has been explained to me to my satisfaction.

I note that the study has been reviewed ***and approved*** by the University of Canterbury Human Ethics Committee.

NAME (please print):

Signature:

Date:

Appendix F – Topic Guide

Topic Guide

The study will consist of semi-structured in-depth interviews that will involve a conversation guided by open-ended questions from a topic guide about intimacy/ intimate communication in relation to AAC use and acquired communication disorders.

The areas included in the topic guide are:

1. The meaning of intimacy for that individual/couple
 - a. What is the meaning of intimacy for you as an individual?
 - b. What is the meaning of intimacy for you as a couple?
2. The role of AAC in intimacy
 - a. Does your AAC play a role in intimacy for you?
 - b. What role does your AAC play in intimacy?
3. The role of the communication disorder in intimacy
 - a. What is the role of your communication disorder in intimacy for you as an individual?
 - b. What is the role of the communication disorder in intimacy for you as a couple?
4. The spouse/partners role in intimacy
 - a. What is your spouse/partners role in intimacy?
5. The change to intimacy pre and post onset of communication disorder
 - a. Have you noticed a change in intimacy since the onset of your/your partners communication disorder?
 - b. What was intimacy like before onset of the communication disorder?
 - c. How is intimacy different since the onset of the communication disorder?